

**THE LEGISLATIVE BLUE RIBBON COMMISSION ON AUTISM:  
Task Force on Early Identification & Intervention**

**January 24, 2007  
10:00AM to 3:00PM**

**The U.C. Center Sacramento  
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**Approaching the Finish Line: Findings, Recommendations, & Next Steps**

**Section I. Priority Gaps & Problems:**

**1. Priority Problem One ~ Appropriate screening, assessment, & intervention of children with Autism Spectrum Disorders:**

Many children are not receiving adequate and appropriate developmental screening and assessment.

- According to the American Academy of Pediatrics (AAP), a majority of pediatricians do NOT use effective means to screen their patients for developmental problems. Surveys indicate that only 23% of pediatricians utilize standard developmental assessment tools and/or instruments in their developmental screening of young children. The Task Force received testimony (Dr. Marc Lerner) that only 20% of pediatricians in Orange County routinely utilized formal developmental assessment tools during routine well-child visits.
- The National Survey of Early Childhood Health (NSECH) has established that almost half (47%) of parents report that their child has never received a developmental screening in the first three years of life. Only 42% of parents of children 0-3 were informed that a developmental assessment was being conducted and only 39% recalled the child was tested with specific tasks or skill requirements. (Halfon et al; "Assessing development in the pediatric office" Pediatrics; 2004; 113: 1926-33).
- Pediatric health care providers often fail to provide adequate developmental screening and other developmental services because they are not well trained; lack adequate assessment measures; pressured by lack of time and also inadequate reimbursement. An Academy of Pediatrics survey (year 2000) identified the following barrier to developmental assessment of children 0-3 years of age:
  - Insufficient time (80%) Time constraints often due to other requirements of "well child care" visit; unable to schedule separate visit for specific developmental evaluation.
  - Inadequate reimbursement (55%)
  - Many managed health plans provide no reimbursement
  - Inadequate or lack of compensation for non-MD resources (i.e. non-medical staff; instruments)

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- Billing Code 96110-no physician work value published on the Medicare physician fee schedule for this code
- Lack of non-MD staff (51%)
- Unfamiliar with codes (46%)
- Lack of referral services for assessment & treatment (34%)
- Lack of training (28%)
- Unfamiliar with instruments (24%)
- The AAP recommends that in addition to a general developmental screening tool, an autism-specific tool should be administered to all children at the 18-month visit since symptoms of autism are often present at this age, and effective early intervention strategies are available. (Pediatrics, Vol. 118 No.1 July 2006; pp. 405-420.) Other experts recommend testing at both 18 months AND at 24 months with an autism-specific tool.  
(<http://www.pediatrics.org/cgi/content/full/119/1/152>)
- 92% of pediatricians do NOT routinely screen for ASD. Lack of knowledge about routine screening tools (62% who did not screen) was the single greatest barrier to routine screening. (Susan dosReis et al; Johns Hopkins Medicine, news release, May 9, 2006)

### **2. Priority Problem Two ~ Helping Parents to Better Access, Utilize, & Navigate Complex Systems of Care:**

Concerns on early developmental abnormalities by parents, family members, and caregivers are often overlooked by healthcare providers. The existing systems of care for ASD are extremely complex and pose challenges to parents, family members and childcare providers in terms understanding and navigating these programs and services.

- Existing gaps in services often preclude effective communication between families and health care providers Many parents of young children have concerns and questions about their child's development that are not being addressed. A national study reported that nearly half of the parents have concerns about their young child's behaviors (48%); speech (45%); and/social development (45%). Another study noted that although 37% of parents of young children have concerns about their child's learning, behavior or development, only 18% were able to discuss these concerns with their pediatrician.
- Studies have established that parents frequently provide an accurate assessment of their child's early developmental delays. Glascoe reported that concerns are usually valid regardless of the parents' own educational background and childrearing experience. (Glascoe, F.P.; "Using Parent's Concerns to Detect and Address Developmental and Behavioral Problems" *Journal of the Society of Pediatric Nurses* 4(1): 1999) Other studies have confirmed that parents can also accurately identify early concerns and abnormalities in various developmental domains that include language, behaviors, attention, and cognitive functions. (Williams et al; "Improving the early detection of children with subtle developmental problems" *Journal of Child Health Care* 8(1): 34-46; 2004.)

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- Mulhern reported that among a group of 100 children with serious developmental abnormalities, 87% had parents who raised concerns prior to their assessment. (Mulhern et. al “Do Parental Concerns Predict a Diagnosis of ADHD?” *Journal of Behavioral & Developmental Pediatrics* 15(5): 348-53. 1994.) Thus, parental concerns on developmental problems are frequently discounted or disregarded by physicians and other healthcare providers even in children who subsequently develop serious developmental delays and disabilities.
- The Task Force believes that almost all parents with young children with ASD experience serious challenges and frustrations in obtaining adequate and timely information from pediatricians and other healthcare providers. This gap not only impedes the child’s timely assessment and intervention but these delays may also have serious long-term consequences and adversely impact the child’s outcome and prognosis.
- Parents, family members and caregivers are often overwhelmed by the incredibly complex and numerous systems of care, programs, services and other options that must be navigated in dealing with ASD. Potentially there are over 40 separate local and/or regional programs, most of which are categorical, that impact a child with ASD. Although regional centers provide parental information and community outreach, many individuals lack access to these supports. Further, this information may be difficult to comprehend, unresponsive to special circumstances nor designed to address a myriad of complexities associated with systems of care.
- The Task Force emphasizes that parents, family members and childcare providers must be more fully and cohesively integrated in the early screening, diagnosis and assessment of children with ASD. Further, it is imperative that parents, family members and childcare providers be given appropriate and adequate information to enable them to effectively navigate and utilize these complex systems.

#### **3. Priority Problem Three ~ Overcoming Disparities & Inequities in Access to Services for Children with Autism Spectrum Disorders (ASD):**

Gaps in existing systems and services may delay and/or exclude the diagnosis/intervention of ASD for certain groups of children.

- The Task Force has received compelling and powerful testimony with regards to the pervasive and critical gaps that exist for children with ASD, and their families, who live in diverse and underserved communities.
- A number of factors are important barriers to appropriate services for these populations and they include:
  - a. Lack of information about the warning signs of ASD.
  - b. Lack of access to doctors, pediatricians, psychiatrists and other health care providers who could assist in the screening, assessment and intervention of ASD.

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- c. The lack appropriate outreach, education and training on issues of diversity, equity and cultural/ethnic sensitivity.
  - d. The lack of services and programs that are culturally appropriate, neighborhood based and integrated within the overall framework of the community.
  - e. Lack of information about state-sponsored programs that provide services to children with ASD (Early Start; Regional Centers, State Preschool Programs; Special Education; First 5 California; and others.)
  - f. Lack of programs and service providers within these communities.
  - g. Lack of childcare and other family support services.
  - h. Inadequate transportation.
- A study in Philadelphia (Dr. David Mandell, NIMH Conference; Oct. 2005) reported that, on the average, the diagnosis of ASD was delayed by almost 2 years among African-American children (7.5 years old) as compared to their Caucasian counterparts (5.5 years old.) Latino children diagnosed at ages intermediate between these two groups.
- African-American children with ASD are more likely to be misdiagnosed as having organic psychoses, mental retardation or selective mutism (Dr. David Mandell.)
- Cultural factors, stigma and other perceptions may foster misunderstandings of ASD as well as the possible mistrust of systems, programs and service providers that are intended to serve these children.
- A multi-state survey of 200 Latino families with disabled children indicated that 52% needed assistance on all items and issues that are measured by the “Family Needs Survey/Family Support Scale.” (Bailey et al. Am. Journal of Mental Retardation. 1999, Vol. 104, No. 5, 437-451.) The Task Force noted testimony that underscored the importance of closing these gaps in the current systems but providing information and parental supports to all families, but particularly those living in diverse and underserved communities.
- Children with certain forms and manifestations of ASD may not receive appropriate assessment and intervention for their disorder. Researchers at The MIND Institute and other universities have established that autism encompasses a broad array of brain-based disorders and deficits. Despite these neuroscientific advances in the early detection and treatment of these disorders, such as Asperger’s Syndrome, many of these children fail to qualify and receive appropriate services from either regional centers or from school districts.
- The 21 regional centers within the DDS system have a variety of different requirements, evaluation standards and other determinations to establish eligibility criteria for children with ASD.

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### **4. Priority Problem Four ~ Transition from Regional Center to School District at 3 Years of Age:**

- An existing gap is the frequent lack of continuity in the programs and services when children with ASD transition from Early Start, and/or regional center services, to programs/services provided by school districts.
- An existing gap is that the types of services and interventions that should be provided by the regional center versus the school districts are contentious and not clearly defined.
- An existing problem (i.e. gap) is that the treatment and interventions of young children with ASD, particularly at three to five years of age, frequently cannot be clearly classified as being either “adaptive” or “educational.”
- An existing gap is that presently children undergo this transition on their third birthday without effective planning, case management, and communication to maintain consistency in their programs and interventions. Consequently, not only does the State incur potential inefficiencies in resource allocations (i.e. duplicative and fragmented services during this transition) but children may also regress during these times.
- An existing gap is that school districts often lack resources and supports to provide effective interventions for young children with ASD. Since there has been a doubling of autistic students in most school districts during just the past four years, preschool programs are often “in limbo.” Not only do these preschool programs lack allocated funds, but they also suffer from a severe dearth of administrative supports. For example, one small school district that educates about 200 ASD students K-12, presently maintains 99 contracts with non-public schools and agencies at a cost of about \$3 million annually. Consequently this district feels that it is under funded and undermanned to adequately meet the needs of its autistic preschool population.
- Current state regulations require that regional centers schedule an IFSP (individual family support plan) and notify school districts when ASD Early Start children turn 2.6 years of age. An existing gap is the lack of oversight and reporting requirements to ensure that regional centers comply with existing state law.
- Existing state law requires that Early Start children receive appropriate screening, assessment and intervention for ASD. A existing gap is the failure to establish oversight and monitoring to ensure appropriate compliance by the regional centers with this regulation.

### **5. Priority Problem Five ~ Professional Development:**

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- Preschool teachers, childcare providers, and other paraprofessionals are inadequately prepared to meet the socio-emotional and behavioral needs of children with ASD.
- Only 32% of childcare providers report being adequately trained to deal with typically developing children.
- One survey (Gilliam & Shahar, *Infants & Young Children*, 2004) reported that even in mainstream preschools, teachers had great difficulties with behavioral issues and had suspended (14.7) or expelled (39.3) at least one student during the past year
- The Task Force emphasizes that the appropriate and adequate training for teachers, school aides, childcare and respite providers, social workers, school administrators, regional center workers, and others across a broad array of issues related to children with ASD is presently presents a huge gap and unmet need.

### **Section II. Strategic Approaches to Addressing & Closing Existing Gaps:**

- Universal availability of developmental screening utilizing appropriate, high-quality screening instruments and tools.
- An effective model(s) should utilize a “triage” approach that is collaborative, integrated, family focused, culturally appropriate & builds upon existing community resources and services.
- The roles and responsibilities of physicians and healthcare professionals must be efficiently defined and appropriately funded.
- There must be societal leadership, community outreach, public awareness and commitment to universal developmental screening/intervention.
- Appropriate and timely referral for assessment interventions must be linked to screening.
- Professional and paraprofessional development, training, and mentoring must be accelerated.
- Parental information, “roadmaps” and other culturally appropriate resources must be established to involve families in the importance of developmental screening & enable families to successfully navigate the systems.

### **Section III. Data & Information:**

- The inclusion and analysis of data (both quantitative and qualitative) should be considered as an important and integral component of the work and recommendations of this Task Force. Such information will be most helpful and important to the future work and recommendations of the Autism Commission. Further, these facts and statistics are significant in identifying and framing and supporting the discussions and recommendations of this work group. The Task Force members are encouraged to consider and recommend pertinent information/data (and/or systems and sources) that may shed light on the following issues:

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- Data that identifies or clarifies the nature of the problem issue (i.e. how the gap was identified.)
- Why this problem issue is important and needs to be addressed.
- Data and information that support the recommendations being offered {i.e. recommendations likely to close the identified gap(s).}
- Data and information that can be used for future outcome measures.
- What additional information and data are available to the Autism Commission that may assist its future work in identifying, analyzing, and correcting/improving key problem areas? For example:
  - How many families apply to regional center for assessment each year- what is the lag time between contact and assessment?
  - What is the lag time between a positive diagnosis and the delivery of service?
  - How many parents of children served by the regional center seek IEP by the school district?
  - What is the average age of the ASD preschooler receiving IEP?
  - What is the lag time between the IEP disposition and the commencement of services?

### **Section IV. Overarching Parameters & Considerations in Task Force Recommendations:**

The Task Force recommendations are a fundamental and critical first step to the Commission's subsequent work and ultimate final recommendations to the Governor and Legislature (September, 2007.) Therefore, it is important that the Task Force report and recommendations are presented in a format that will lend itself to the following outcomes:

- Clear and complete understanding of this report by the Autism Commission.
- Recommendation(s) must be supported by strong case statement, policy analysis and specific outcome measures.
- Recommendation(s) must be strategic, realistic and "doable."
- The recommendation(s) can be incremental (i.e. pilot project.).
- The reports and recommendations from the three Task Force work groups (Early Identification; Education; "Aging Out") will be presented and discussed at the next hearing of the Legislative Blue Ribbon Commission on Autism (date pending but likely at the end of February.) Subsequent to the actions (including possible modifications) by the Commission, these recommendations will undergo the following:
  - A series of "public vetting" & discussions.

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- Input and recommendations from a broad and varied array of stakeholders and other interested parties.
- Analysis and input from a variety of government organizations and agencies.
- Final report and recommendations by the Autism Commission to the Governor and Legislature, September 2007.

### Section V. Discussion of Specific Proposals:

The Task Force has been requested to submit a series of specific proposals and recommendations to the Autism Commission to improve the appropriate screening, diagnosis, assessment and intervention of children with ASD. The following are a series of **possible** recommendations (i.e. “discussion points”) that have been formulated after a careful review of the discussions and recommendations emanating from the first two Task Force meetings. It must be emphasized, that they are being offered merely as “starting points” (intentionally broad descriptions) and are not intended to be “proscriptive.”

However, the Task Force must conclude this meeting with a series of specific and limited recommendations that are prioritized and hopefully established by consensus. Thus, the following concepts are offered (not in any particular order of importance) in hopes that they will stimulate a creative discussion and assist the Task Force in reaching its final conclusions:

1. Recommendations that would create a pilot project of pooled funding to create a seamless system of service delivery between the regional centers and state department of education and local school districts.
2. Recommendations that DDS implement its best practices guidelines (*Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment*; CA Dept. of Developmental Services, 2003) for screening and diagnosis of children in the Early Start Program who show signs and risks of ASD.
3. Recommendations that DDS perform a needs assessment to determine if there are sufficient numbers of qualified professionals (as defined by *Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment*) to conduct ASD screening, diagnosis and assessments in a timely, appropriate, and accurate manner. If the survey findings establish insufficient numbers of professionals, than DDS shall take appropriate steps and actions to promote training opportunities to expand and enhance the number of professionals qualified to do ASD evaluations.
4. Recommendations that would establish centralized, statewide, technology-based, on-line, culturally appropriate, resource center that would be available to parents, family members, caregivers, and other stakeholders to accomplish, at a minimum, the following:
  - i. obtaining needed information on ASD.
  - ii. Improve access to services, programs and systems of care that relate to the screening, diagnosis, assessment, and intervention of ASD.



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- iii.* Improve the utilization and navigation of services, programs and systems of care that relate to the screening, diagnosis, assessment, and intervention of ASD that provide services to children with ASD.
- 5.** Create alternative professional and paraprofessional certification program in collaboration with CDE and Teacher Credentialing and Licensing.
- 6.** Recommendations that would provide incentives to institutes of higher education for students who pursue career pathways (both professional and paraprofessional) that address the workforce needs of working with children with ASD.
- 7.** Recommendations to implement pilot projects in underserved communities to conduct screenings to determine the number of unidentified children in these communities; to assess and identify potential barriers to screening, diagnosis, assessment, and intervention for children with ASD; and to provide recommendations on the corrective actions required to reduce and/or eliminate these barriers.
- 8.** Recommendations to develop a statewide media based, multilingual and culturally appropriate, public announcement and community outreach campaign on the importance of early developmental screening and the warning signs of ASD.
- 9.** Recommendations that would evaluate existing statewide programs related to early developmental screening (such as the First5CA Special Needs Project) and to provide recommendations by which such programs could be either expanded and/or modified to provide more effective screening, diagnosis, assessment and intervention for children with ASD.
- 10.** Recommendations that would determine whether there are subsets (i.e. populations) of infants and children (i.e. premature infants or otherwise medically fragile; exposed to alcohol and/or other toxic substances; children suffering abuse and/or neglect; infants and young children in foster care; siblings of children with ASD; and/or other high risk conditions) that would justify establishing a protocol for the widespread screening, diagnosis, assessment, and intervention (if needed) for all such children within that identified subset.
- 11.** Recommendations that would provide a needs assessment for a centralized, multidisciplinary voluntary registry for children who are identified by parents or guardians as having concerns, manifestations or other evidence (as defined by appropriate developmental experts) of ASD. Further, to determine whether symptoms and/or other manifestations of ASD should be considered as a “reportable condition” by certain designated professionals.
- 12.** Recommendations that would implement a pilot project of children who are served by CHDP to accomplish the following:
  - i.* To determine if additional reimbursement should be provided to improve the “out of office screening” of children with ASD.
  - ii.* To determine if additional reimbursement is appropriate and cost-effective to facilitate and improve the assessment and referral of children with ASD who are seen by these healthcare providers.
  - iii.* To determine if additional reimbursement to these healthcare providers is appropriate and cost-effective for ongoing “case management” for certain categories of children with severe and complex ASD.